



DEVELOPMENTAL PROGRAMS BULLETIN

COMMONWEALTH OF PENNSYLVANIA DEPARTMENT OF PUBLIC WELFARE

DATE OF ISSUE

February 13, 2009

EFFECTIVE DATE

February 13, 2009

NUMBER

00-08-15

SUBJECT:

**Disability Rights Network Access to
Records and Joint Investigations**

BY:

Kevin T. Casey
Deputy Secretary for Developmental Programs

SCOPE:

Administrative Entity Administrators or Directors
County Mental Health and Mental Retardation Program Administrators or Directors
Supports Coordination Organizations
Providers of Mental Retardation Services
State Center Facility Directors
NonState Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR)
Directors

PURPOSE:

The purpose of this bulletin is to communicate the merger of Pennsylvania Protection and Advocacy, Inc., (PP&A) and Disabilities Law Project (DLP) to create the Disability Rights Network (DRN), clarify procedures for site visits and access to records by DRN, and to issue the Office of Developmental Programs (ODP) and DRN joint investigation protocol.

BACKGROUND:

PP&A was an independent, private, non-profit organization designated by the Governor of Pennsylvania as the agency to provide protection and advocacy for persons with developmental disabilities, mental illness, and other disabilities. DLP has worked closely with PP&A representing persons with disabilities and advocacy organizations.

PP&A's authority is conferred by the "Developmental Disabilities Assistance and Bill of Rights Act" Public Law (P.L.) 99-319 of 1986, amended in 1988 as P.L. 100-509. The law was most recently amended in 2000 as P.L. 106-402. The law includes the protection of legal and human rights of persons with developmental disabilities. DRN operates under the federal regulations at 45 CFR 1386, entitled Formula Grant Programs.

A protection and advocacy agency has the authority to investigate incidents or complaints of abuse and neglect of persons with disabilities if there is probable cause or if incidents or complaints are reported to the agency, as well as the right to access facilities, individuals receiving services, and individual records under certain

COMMENTS AND QUESTIONS REGARDING THIS BULLETIN SHOULD BE DIRECTED TO:

The Appropriate Developmental Programs Regional Office

circumstances. Since, at times, investigations had occurred jointly with the protection and advocacy agency and ODP, a protocol to guide both entities is necessary.

This bulletin replaces Bulletin SC-92-01, “*Agreement Between the Office of Mental Retardation and PP&A*”, issued September 28, 1992. This bulletin also replaces Bulletin 00-03-02, “*Site Visits and Access by Pennsylvania Protection and Advocacy, Inc*”, issued February 19, 2003, as it applies to the Office of Developmental Programs. However, Bulletin 00-03-02 remains in effect for the other Department of Public Welfare Offices that co-signed the bulletin.

DISCUSSION:

Merger of PP&A and DLP

Effective February 1, 2007, PP&A and DLP merged to form the Disability Rights Network of Pennsylvania (DRN). DRN will provide the full range of legal, policy, and advocacy services necessary to protect and advance the rights of persons with disabilities. DRN will also continue to offer all of the legal and advocacy services PP&A and DLP have provided to persons with disabilities for many years, including advice and technical assistance via a toll-free phone number; individual, systemic, and policy advocacy; systemic-impact litigation; and other legal services. DRN is the designated protection and advocacy agency for Pennsylvania.

DRN Authority

DRN has wide-ranging authority to protect the rights of and advocate for individuals with developmental disabilities under the Developmental Disabilities Act and its implementing regulations, 45 CFR 1386. DRN's federal authority supersedes any inconsistent state or local laws and regulations, including the Child Protective Services Law and the Peer Review Protection Act. DRN's federal authority is not overruled by or inconsistent with the Health Insurance Portability and Accountability Act of 1996 and implementing regulations.

DRN has the authority to:

- Investigate incidents or complaints of abuse and neglect of individuals with developmental disabilities when such incidents or complaints are reported to DRN or DRN has probable cause to determine that such incidents occurred.
- Pursue legal, administrative, and other appropriate remedies to ensure the protection of, and advocacy for, the rights of individuals with developmental disabilities.

DRN has the right to:

- Reasonable, unaccompanied access to public and private facilities that provide services, supports, and other assistance for individuals with developmental disabilities. Entities subject to this bulletin shall place no restrictions on DRN when it conducts unannounced visits at reasonable times. DRN's activities will be conducted so that minimal disruption to daily or scheduled activities occurs.

DRN will advise the entity and ODP of any findings that require immediate attention at an exit interview.

- Unaccompanied access to all individuals residing in a facility at reasonable times, including individuals who have legal guardians or conservators. This includes the opportunity to meet and communicate privately with individuals by telephone, mail, and in person.
- Have access to the records of an individual with developmental disabilities when the circumstances set forth in the following section are satisfied.

To the extent that an entity has questions concerning DRNs authority under the Developmental Disabilities Act, it should contact its legal counsel.

POLICY:

DRN Access to Records

DRN must be given access to all records of an individual with developmental disabilities in any of the following three circumstances:

1. When an individual with a developmental disability authorizes DRN to have access to his or her records or, if applicable, when the legal guardian, conservator, or representative authorizes DRN to have access to the individual's records.
2. When:
 - a. An individual with a developmental disability, due to his or her mental or physical condition (including death), is unable to authorize DRN to have access to his or her records; and
 - b. The individual does not have a legal guardian, conservator, or legal representative, or his or her legal guardian is a state or local government entity; and
 - c. DRN has received a complaint about the individual's status or treatment or DRN has probable cause to believe that the individual has been subject to abuse or neglect.
3. When:
 - a. An individual with a developmental disability has a legal guardian, conservator, or legal representative; and
 - b. DRN has received a complaint about the individual's status or treatment or DRN has probable cause to believe that such individual has been subject to abuse or neglect; and
 - c. DRN has made a good faith effort to contact the individual's legal guardian, conservator, or legal representative upon receipt of his or her name and address and offered assistance to resolve the situation; and
 - d. The individual's legal guardian, conservator, or legal representative has failed or refused to act on behalf of the individual.

A legal guardian, conservator, or other legal representative means a person appointed and regularly reviewed by a state court who has the authority to make all decisions on

behalf of an individual with developmental disabilities. A legal guardian, conservator, or legal representative does not include the following:

- A person acting as a representative payee.
- A person acting only to handle financial payments.
- Attorneys or other persons acting on behalf of an individual with a developmental disability only in individual legal matters.
- Officials responsible for the provision of treatment or habilitation services to an individual with developmental disabilities.
- The executor of the estate of an individual with developmental disabilities.

The records that DRN is entitled to access include, but are not limited to, the following:

- Records prepared or received in the course of intake, assessment, individual service plans, service notes, agency progress notes, communication logs, evaluation, education, training, and other supportive services.
- Financial records.
- Medical records.
- Discharge planning records.
- Monitoring reports.
- Investigation reports and materials.

An entity that receives a written request from DRN for records of an individual with developmental disabilities must provide DRN with access to those records no later than 3 business days after the DRN makes the written request. If an entity denies DRN's request for records, it must provide DRN with a written statement of the reasons within 3 days of the written request. In the case of a denial for alleged lack of authorization, the written statement must include the name of the individual's legal guardian, conservator, or other legal representative.

In a case involving the death of an individual with developmental disabilities, or if DRN determines that there is probable cause to believe that the health or safety of the individual is in serious and immediate jeopardy, the entity must provide DRN with immediate access to the records. Immediate access is defined as "within 24 hours after DRN makes a request". In this situation, DRN does not need to secure the consent of another party (such as the legal guardian, conservator, or legal representative) before it receives those records.

Joint DRN and ODP Investigation Protocol

When indicated, a joint investigation including representatives of DRN and ODP will be conducted as a collaborative effort to ensure the health and welfare of individuals.

The determination to investigate applies to the following:

Deaths:

Bulletin 6000-04-01, "*Incident Management*", requires the ODP Regional Office to investigate the deaths of individuals who reside in provider-operated settings as well as any deaths that may occur in nonresidential licensed settings. The ODP Regional

Program Manager (RPM) or their designee may request the participation of a DRN certified investigator as deemed necessary by the RPM. DRN will use its discretion in allocating resources for this purpose.

Incidents other than Deaths:

Other incidents will be investigated following Bulletin 6000-04-01, "*Incident Management*" or as directed by the RPM or their designee. Similarly, the RPM or their designee may request the participation of a DRN certified investigator as deemed necessary or appropriate. DRN will use its discretion in allocating resources for this purpose.

State Centers:

All incidents will be investigated following Bulletin 6000-04-01, "*Incident Management*" or as directed by the State Center Facility Director or their designee. Similarly, the State Center Facility Director or their designee may request the participation of a DRN certified investigator as deemed necessary or appropriate. DRN will use its discretion in allocating resources for this purpose.

DRN Requests:

DRN may request ODPs involvement in investigating incidents or complaints reported directly to DRN that may or may not fall within the scope of the Incident Management Bulletin. The RPM, State Center Facility Director, or designee will use discretion in recommending the allocation of resources for this purpose. The recommendation must be approved by the Deputy Secretary of ODP. If the RPM, State Center Facility Director, or designee assigns a Regional Office or State Center certified investigator to work with DRN, then the Regional Office or State Center investigator must be considered the lead investigator for purposes of fulfilling the requirements of the Incident Management Bulletin only. DRN may also request of the RPM, State Center Facility Director, or designee that DRN be involved in an investigation that the Regional Office or State Center is conducting. Granting such a request will be at the sole discretion of the RPM, State Center Facility Director, or designee, with the understanding that the Regional Office or State Center certified investigator will be the lead investigator as described above.

DRN may conduct their own investigations as it deems necessary according to federal mandates.

Roles:

ODP has the responsibility and authority to ensure certified investigations are completed according to the Incident Management Bulletin and Certified Investigation training guidelines. The ODP representative will be a Certified Investigator and will take the lead on the investigation. The DRN representative will actively participate in the investigation only if the representative is a Certified Investigator. DRN representatives who are not Certified Investigators may participate in joint investigations only as observers. Certified Investigators from DRN will assist in planning and carrying out each step of the investigation. If a DRN representative is a witness to an incident, then that person cannot participate in the investigation.

Timeline:

Within 24 hours of notification of a reportable incident, the RPM, State Center Facility Director, or designee should contact DRN by telephone if the RPM or State Center Facility Director has determined the need for DRN involvement in the investigation. The Certified Investigation process and timeline will be followed. Similarly, DRN will contact the RPM, State Center Facility Director, or designee within 24 hours of the report of a particular incident or complaint for which DRN desires a joint investigation. If the incident or complaint does not require a Regional Office or State Center investigation, the RPM or State Center Facility Director will determine whether Regional Office or State Center resources will be allocated for the investigation, or if the appropriate County Program or Administrative Entity will be asked to conduct an investigation.

Communication:

All information related to a joint investigation will be shared between ODP and DRN. It is critical that ODP and DRN maintain close communication during any joint investigation. The Division of Community Services Director or the Division of ICF/MR Services Director will notify the appropriate ODP Program Manager when a joint investigation is requested.

NOTE: DRN is federally mandated to maintain the anonymity of the reporter if requested by the reporter.

Reports:

When a joint investigation occurs, the ODP investigator will complete the investigative final report with input from the DRN investigator. DRN will have an opportunity to review the report prior to ODP inputting the investigative findings into the Home and Community Services Information System (HCSIS). The ODP certified investigator will enter all investigative records and enter the summary of the investigative findings into HCSIS. ODP will share a copy of the final report with DRN. Both investigators must sign the hard copy of the report.

Concurrence:

If concurrence regarding the investigation findings cannot be reached between the ODP and DRN investigators, then the DRN investigator will be expected to complete a separate memo that contains the points of disagreement. The RPM, State Center Facility Director, or designee will review the DRN memo and meet with the ODP investigator to determine if consensus can be reached. The RPM, State Center Facility Director, or designee will direct the ODP investigator to make any changes to the investigative final report that the RPM, State Center Facility Director, or designee deems necessary. Should DRN disagree with the decision of the RPM, State Center Facility Director, or designee, the DRN Executive Director may notify ODP in writing of DRNs disagreement. DRNs written notice should be sent to ODPs Deputy Secretary, with copies of the notification sent to the Bureau Director of Supports for People with Intellectual Disabilities, the Division of Community Services Director or the Division of ICF/MR Services Director as appropriate, and the RPM or State Center Facility Director. ODP Central Office will make the final decision regarding the content of the investigative

report. After the final decision is made, the investigative findings will be entered into HCSIS by the Regional Office or State Center Certified Investigator.

This protocol has no bearing on DRNs authority to pursue other administrative and legal remedies.

OBSOLETE BULLETINS:

Bulletin SC-92-01, *“Agreement Between the Office of Mental Retardation and PP&A”*, issued September 28, 1992.

Bulletin 00-03-02, *“Site Visits and Access by Pennsylvania Protection and Advocacy, Inc.”*, issued February 19, 2003 as it applies to the Office of Developmental Programs only. Bulletin 00-03-02 remains in effect for the other Department of Public Welfare offices that co-signed this bulletin.

ATTACHMENT TO THE BULLETIN:

The Developmental Disability Assistance and Bill of Rights Act of 2000